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EDITORIAL: Decision Aids for Organ Transplant Candidates

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Organ transplantation presents numerous difficult treatment decisions for patients with end-stage organ disease. Common decisions include whether to accept or decline an offered organ or whether to pursue living donor transplantation. The most challenging decisions are life and death decisions that involve making a tradeoff between waiting for a good quality organ, which can confer longer survival but with the risk of death from waiting too long, versus accepting any quality organ, which enables transplantation sooner but with the risk of shorter survival post-transplant or post-transplant complications, including infections. Such tradeoffs inherent in any treatment decision can be overwhelming and patients may turn to transplant providers for help or shared decision making.[1]

Transplant providers helping patients to make treatment decisions may find it difficult to communicate risks associated with each option in a clear, understandable fashion, particularly for increased risk donor organs. Increased risk donor organs come from donors who engaged in behaviors or have characteristics that make them more likely to be infected with Hepatitis B, Hepatitis C, and/or HIV. Fortunately, contemporary donor screening makes the risk of transmission of infection from the donor to the recipient a small, but true risk. Research studies document that patients do not fully grasp information about risks of medical interventions and the challenges of communicating such uncertainty.[2]

Decision aids are increasingly being developed to support patients in making difficult treatment decisions. Decision aids are valuable for increasing knowledge of options, creating more realistic expectations, reducing decisional conflict, and fostering communication.[3,4] Web-based decision aids have been shown to effectively increase patients' comprehension during informed consent for routine medical and surgical care[5–10] by 9%–25%,[9,10] as well

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as increase recall of information,[10] accuracy of risk estimates,[6] satisfaction with information delivery[9,10] and information received.[6]

While decision aids can be found across diverse clinical contexts, few have been developed in the transplant context: for live liver donor candidates or deceased donor families.[11,12] As reported in this issue of *Liver Transplantation*, Volk and colleagues are among the first to develop a decision aid for transplant candidates. Volk and colleagues developed and pilot tested a new decision aid designed to increase liver transplant candidates' knowledge about organ quality. They have done an excellent job overcoming challenges in communicating risk information through the use of an interactive sliding bar that generates, and a graph that depicts, the patient's selected risk of experiencing graft failure according to their own Model for End-Stage Liver Disease (MELD) score and translates this risk into a proportion of liver grafts that would be turned down to achieve this risk level.

One stated aim of the study was to decrease candidates' reluctance to accept organs of less than perfect quality. Accordingly, Volk and colleagues' decision aid does not appear to fully align with the traditional role of decision aids as balanced and neutral. In this regard, their decision aid appears to fit with a new, controversial role of decision aids in nudging patients toward a particular option.[13] Further, decisions aids should explicitly convey their non-directive, unbiased purpose in their instructions. However, it is unclear whether Volk and colleagues' decision aid itself explicitly conveyed the intention to decrease candidates' reluctance to accept such organs.

An interesting finding is that their decision aid significantly increased patients' willingness to accept 'less than perfect livers,' regardless of MELD score. This finding counters an expectation that patients with higher MELD scores would have expressed greater willingness than those with lower MELD scores. Should patient attitudes drive actual decision-making for liver (and other organ) transplant candidates, one would expect to observe an increased use of less than perfect quality organs and a simultaneous reduction of deaths on the waiting list. This outcome supports United Network for Organ Sharing's goals of increasing organ availability and access to transplantation. However, an unintended consequence may be a greater preponderance of complications and mortality in the short-term, as Volk and colleagues point out. Individual transplant centers should clearly discuss with transplant candidates their approach to making organ offers to individual recipients, particularly for organs of 'less than perfect quality,' so that patients can select a center that aligns with their treatment priorities. Alternatively, centers should engage transplant candidates to fully understand their willingness to accept organs over a range of quality.

A common misconception about decision aids is that they replace patient-provider communication. Volk and colleagues correctly report that they intend for their decision aid to *supplement* patient-provider discussions. As providers remain central to shared decision making, it is essential that providers fully comprehend issues pertinent to organ quality to effectively communicate with patients. However, in our survey of 90 non-physician clinicians across the U.S. who were involved in the education and/or informed consent process for increased risk donor organs, we found that many, if not most, providers did not have sufficient knowledge of what increased risk donor organs are, of what the risks of

transmitting infectious diseases are, or did not have sufficient confidence to obtain informed consent about increased risk donor organs.[14] Thus, educational decision aids may also prove useful for transplant providers.

While significant knowledge gains were observed by Volk and colleagues after patient use of the decision aid, only three questions were asked focusing on the chance of death while waiting on the waiting list for 3 months, and the possibility of getting HIV or Hepatitis B from a liver transplant. Although Volk and colleagues intended to keep the decision aid brief (mean: 15 minutes), the shorter the intervention exposure time, the less educational content that can be provided and then tested. Other knowledge items may be important to assess that could influence candidates' decision making, e.g., the donor's behavior that contributed to an organ donor becoming at increased risk, or the behavior's associated risk of undiagnosed infection, or the rate of risk transmission.

Nonetheless, a notable finding is that waiting list patients had relatively low levels of knowledge about organ quality despite having already received standard education about extended criteria organs and increased risk donor organs. Considering that transplant centers vary in the format and timing of education about transplantation,[15] it is not surprising that patients in Volk and colleagues' study reported poor levels of knowledge. This suggests that transplant centers should revisit their educational materials, communication procedures, and informed consent forms, ensuring that they are prepared at a low literacy level and comprehensive enough.

As a preliminary step toward establishing proof of concept and feasibility, Volk and colleagues' decision aid makes a great contribution to the transplant field. Further research is needed using a randomized controlled trial to establish effectiveness.

As there are many difficult decisions within the transplant context, decision aids for other transplantation- or donation-related decisions should be developed to support both the patient and the provider in the decision-making process. Ultimately, research is needed to ascertain the types of decisions for which potential recipients and donors would like to use a decision aid.[1] Further, Volk and colleagues' decision aid is specific to liver candidates; additional decision aids will need to be developed and validated for other organ transplant populations.

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References

1. Gordon E, Butt Z, Jensen S, et al. Opportunities for shared decision making in kidney transplantation. Am J Transplant. 2013; 13(5):1149–1158. [PubMed: 23489435]
2. Politi M, Han P, Col N. Communicating the Uncertainty of Harms and Benefits of Medical Interventions. Med Decis Making. 2007; 27:681–695. [PubMed: 17873256]

3. Stacey D, Bennett C, Barry M, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database of Systematic Reviews. 2011; (10)

4. O'Connor A, Bennett C, Stacey D, et al. Decision Aids for People Facing Health Treatment or Screening Decisions. Cochrane Database of Systematic Reviews. 2009; (3):CD001431. [PubMed: 19588325]

5. Schenker Y, Fernandez A, Sudore R, Schillinger D. Interventions to improve patient comprehension in informed consent for medical and surgical procedures: A systematic review. Medical Decision Making. 2011; 31(1):151–173. [PubMed: 20357225]

6. Cull A, Miller H, Porterfield T, et al. The use of videotaped information in cancer genetic counselling: a randomised evaluation study. British Journal of Cancer. 1998; 77(5):830–837. [PubMed: 9514066]

7. Flory J, Emanuel E. Interventions to improve research participants' understanding in informed consent for research: A systematic review. JAMA. 2004; 292(13):1593–1601. [PubMed: 15467062]

8. Beamond BM, Beischer AD, Brodsky JW, Leslie H. Improvement in surgical consent with a preoperative multimedia patient education tool: a pilot study. Foot Ankle Int. 2009 Jul; 30(7):619–626. [PubMed: 19589307]

9. Karunaratne AS, Korenman SG, Thomas SL, Myles PS, Komesaroff PA. Improving communication when seeking informed consent: a randomised controlled study of a computer-based method for providing information to prospective clinical trial participants. Med J Aust. 2010 Apr 5; 192(7): 388–392. [PubMed: 20367586]

10. Cornoiu A, Beischer AD, Donnan L, Graves S, de Steiger R. Multimedia patient education to assist the informed consent process for knee arthroscopy. ANZ J Surg. 2011 Mar; 81(3):176–180. [PubMed: 21342392]

11. Freeman J, Emond J, Gillespie B, et al. Computerized assessment of competence-related abilities in living liver donors: the Adult-to-Adult Living Donor Liver Transplantation Cohort Study. Clin Transplant. 2013; 27(4):633–645. [PubMed: 23859354]

12. Richter T, Buhse S, Kupfer R, Gerlach A, Mühlhauser I, Lenz M. Development of a decision aid on post mortem organ donation - somewhere between evidence uncertainty, fears, and ethical and moral values [Article in German]. Z Evid Fortbild Qual Gesundhwes. 2013; 107(9–10):622–631. [PubMed: 24315333]

13. Blumenthal-Barby J, Cantor S, Russell H, Naik A, Volk R. Decision aids: when 'nudging' patients to make a particular choice is more ethical than balanced, nondirective content. Health Aff (Millwood). 2013; 32(2):303–310. [PubMed: 23381523]

14. Gordon E, Mullee J, Beauvais N, et al. Education and Informed Consent about Increased Risk Donor Kidneys: A National Survey of non-Physician. Transplant Infectious Disease. 2014; 16(2): 251–260. [PubMed: 24621147]

15. Gordon E, Caicedo J, Ladner D, Reddy E, Abecassis M. Transplant Center Provision of Education and Culturally and Linguistically Competent Care: A National Study. American Journal of Transplantation. 2010; 10(12):2701–2707. [PubMed: 21158005]